

tant step involves respectfully listening to patients describe their symptoms, without labeling the symptoms prematurely as predominately psychologic. The physician should avoid cutting the patient off in midsentence. Second, every illness has both a psychologic and a physical component, but an accurate assignment of percentage for each may not be possible. Acknowledging the experience for patients increases the likelihood that they will work with you to get better. Third, reassure patients that, although they may continue to have symptoms, their level of functioning will improve. Finally, do a complete assessment, which should include an occupational and environmental history to understand possible triggers. If this health concern is aggressively attended to early, the pitfalls of patients developing chronic illness may be avoided.

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When AIDS became a chronic disease

"The flu gives you a fever, but your mother puts you to bed."

Folk saying

A basic tenet of medical anthropology is that illness is socially constructed. Agents of disease produce physical symptoms in people, but relatives, friends, and health professionals surrounding a sick person classify and interpret those symptoms to determine if he or she is ill. How a society interprets and classifies symptoms, prescribes treatment, and assigns the sick role vary with many factors, from geographic location to political economy.

In June 1989, Samuel Broder, then head of the Na-

tional Cancer Institute, declared in a speech at the international AIDS meeting in Montreal, Quebec, that AIDS was a chronic illness and that treatment should follow the model of cancer.¹ This public statement marked a shift in the social definition of AIDS from an acute to a chronic illness, a shift with economic and cultural repercussions for the treatment and understanding of AIDS at the national, local, and individual levels.

CULTURE AND ECONOMY

The relation between political economy and cultural concepts of disease and treatment is illustrated in Fabrega's comparison of contemporary foragers and village societ-

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Summary points

- Illness is socially constructed. We are not sick until those around us agree that we are. The social construction of chronic illness and the sick role depend on a complex social structure
- AIDS is now viewed in the Western world as a chronic, life-threatening illness with two phases: HIV infection and AIDS
- The redefinition of AIDS affects all levels of social life—international, national, local, and individual
- People who are HIV-positive or have AIDS face the stigma of chronic illness. Stigma reflects a discredited and negative social identity
- The chronic character of AIDS, with periods of crisis alternating with periods of stability, requires those with AIDS to continually reorganize their view of their life's expected course

ies.² Nomadic foragers hunt animals and gather plants for food that is distributed equally among all members. Labor is also divided equally. Although men generally hunt and women gather, most members of the society can perform any essential task. Because group size is small—30–50 people—every member's labor is important. Because foraging communities lack surpluses of food, nonproductive members consume precious resources and threaten the group's survival. Given these features, it follows that symptoms defined as disease are limited to acute conditions that are dramatic and life threatening or prevent the person from working. Moreover, foragers experience few chronic illnesses, such as parasites or epidemics of infectious diseases like measles, because they move frequently, and few of them live together in one place. Consequently, treatment is limited to those who are dangerously ill, with minor acute ailments and chronic illnesses largely ignored.

In contrast, in village societies where food is cultivated, enough surplus exists that some members of the society can be marginally productive in agriculture or husbandry. With this comes greater division of labor, including individuals who acquire specialized skills in diagnosis and healing. At this level of social organization, adopting the sick role—that is, being relieved of normal roles and obligations to get well—becomes possible. In addition, because of the sedentary character and dense population of village life, such chronic diseases as parasitic infections and acute viral and bacterial infections are endemic. Thus, the range of defined diseases expands, and the boundaries between illness and health become less clear.

In the industrialized market economy of the United States, with its many specialized jobs and tasks, the role of one person in production is minor, and enough surplus wealth exists to support many nonproductive people. Public resources expended for sanitation, vaccinations, and the development of antibiotics have reduced the incidence of

acute illness. Consequently, chronic illnesses have become more common. Moreover, medical specialization and technology create chronic conditions by rescuing patients from life-threatening situations that nonetheless leave a residual loss of function or chronic illness.

CULTURAL DEFINITIONS OF ACUTE AND CHRONIC

Acute and chronic are culturally defined categories of illness recognized by health care professionals and their clients. The difference between these categories is more than a matter of time; their meaning to society and to the individual differs significantly. Acute illnesses are characterized by a sudden onset, obvious signs and symptoms, and some limitation of normal function—even if only an annoying cough or low-grade fever. Treatment is either supportive or curative, and resolution to death or normal activity ensues. The duration consists of days or weeks. Acute illness follows a predictable course; if it does not, it is redefined as chronic illness. One of the most pervasive features of human culture is the use of symbols and metaphors. In the United States, metaphors for acute illness arise from the arena of war: viruses invade, bacteria attack, and parasites infest. Treatment consists of strengthening defenses, killing bacteria, or battling an infection. We speak of heroic measures and rescue operations.

Chronic illness, in contrast, may arise from an acute episode that does not resolve to full health—for example, a diabetic coma. The course of a chronic illness is uncertain and unlimited in time, usually characterized by alternating periods of acute crisis and remission. The disease may not produce visible symptoms, as with hypertension. Treatment is directed at relieving symptoms and slowing degeneration, not effecting cure. Metaphors for chronic illness are drawn from the language of business: symptoms are managed, crises are averted, support systems are organized, and regimens are designed. Whereas the battle against acute illness is dramatic and heroic, the management of chronic illness, despite its complexity, is banal. Reflecting these priorities, our health care system rewards surgeons more than internists.

AIDS AS A CHRONIC ILLNESS

At the international level, inequality in wealth between developed and developing nations has produced essentially two types of AIDS: chronic AIDS in the Western world, where resources are available for treatment with zidovudine and other drugs, and acute AIDS in the developing world, where there are no funds for such treatments.³

On the national level, AIDS as a chronic illness means a shift in the priority it receives in national health policy and a growing inequity in how resources for its treatment are allocated among the population. Despite initially being

seen as confined to gay men, once transmission to women, children, and heterosexual men was identified, its control was given high priority from public health officials and government agencies. Political activity by gay men, most of whom were white, deliberately played on fears of virulence and heterosexual transmission and was effective in securing government support for research and treatment.⁴

Advocates for research and funding for the management of AIDS must compete with advocates for people suffering from other chronic, life-threatening illnesses—for example, cancer, diabetes mellitus, and hypertension. The recognition that most new cases of AIDS occur among heterosexuals has changed public perceptions and policy in several ways. First, AIDS has become normalized in the sense that more of the population is viewed as vulnerable to infection. Although this is helpful in reducing the stigma associated with the disease and takes some of the pressure off the gay community, it has broken down some of the political alliances that mobilized advocacy for people with AIDS in the 1980s. Secondly, the incidence of AIDS is several times higher among African American and Hispanic men, women, and children than among white men, women, and children. Given that minority populations have lower rates of health insurance coverage, treating AIDS means increasing public expenditures on a broad scale. As a chronic illness, AIDS is another problem in a health care system already riddled with problems.⁴

Chronic illnesses, because of their uncertain course and often complicated, multisystem treatments, require the mobilization of a network of family, friends, health care professionals, and services for their management. Organizations that arose to assist people dying of AIDS, whose social networks had been decimated by the epidemic, have had to change their orientation to providing episodic assistance during acute crises. Project Angel Heart in Denver, Colorado, provides meals to people with AIDS who cannot prepare meals for themselves or who need supplemental nutrition because of their treatment regimens. Although their clients may have long periods during which they do not need the service, clients may stay on the rolls for many years instead of only a few months. Medical regimens and appointments with physicians, therapists, nutritionists, and other specialists require enormous expenditures of time, energy, and resources on the part of not only people with AIDS but also their friends and family. The health of caregivers may be adversely affected as well.⁵

Writing in 1988, Susan Sontag asserted that “It seems that societies need to have one illness which becomes identified with evil, and attaches blame to its ‘victims.’”⁶ Certainly, in the early 1980s, AIDS, with its virulence, epidemic spread, wasting of the body, and sexual mode of transmission, served that social purpose well. Now that it is viewed as a chronic, life-threatening but not immedi-

ately fatal illness present in the general population, its power as a metaphor for evil is diminished. The development of the category HIV positive, a result of treatment that can forestall the progression to AIDS, has also alleviated some of the public fear of the disease and those who have it. This is good news for those with AIDS; however, chronic illness brings its own social challenges.

THE STIGMA OF CHRONIC DISEASE

Most chronic illnesses carry a stigma. Sociologist Erving Goffman defined a stigma as “. . . a failing, a shortcoming, a handicap.”⁷ Every society embodies models or paradigms of how a healthy, normal, whole person appears, acts, feels, and thinks. An attribute that causes the person to deviate from normal is a stigma. Because the attribute violates the expectations of normal behavior or appearance, it is discrediting and negative. Deviant people are viewed as somehow responsible for their abnormality; thus, their moral character is also challenged.⁷ Moreover, stigmatized people share society’s view of what is normal. They know they fail to match the model.

Chronic illness can be stigmatizing in a variety of ways—by visible disabilities and abnormalities such as an amputated limb, by limited independence or mobility (for example, the use of a wheelchair or a cane); by impairing a normal daily routine (for example, frequent hospitalizations or the inability to work full time or at all), or by the diagnosis itself and the impending death it implies. Even in the absence of visible symptoms, people who are HIV positive are stigmatized once their diagnosis is known. Reactions are rarely predictable, thus generating a great deal of anxiety in encounters with strangers or new acquaintances.

People cope with stigma in many ways. Some openly declare their diagnosis and challenge those around them to treat them differently. Some hide and retreat into a self-imposed isolation. Some may restrict their social life to people who are also HIV-positive or who have AIDS.



John West, who has AIDS, teaches and is working on his master’s degree

AP Photo/Susan Ragan

What pervades social interaction is that the person with AIDS or HIV infection is expected to manage the awkward and difficult emotions that may arise.⁸

Finally, living with a chronic disease requires a different view of the self and the meaning of the illness and one's life. When AIDS was an acute illness, the diagnosis was delivered as a death sentence. Wills were written, funeral plans made, and possessions distributed to friends and family. Many long-term survivors have described the reorganization their lives had to undergo as they realized that if, indeed, they were going to die, it might not be anytime soon. In some respects, the uncertainty of chronic illness is as difficult to live with as the knowledge that you will soon die.

BELIEFS ABOUT NORMAL LIFE

All societies hold beliefs about what the normal life course should be. Anthropologist Gay Becker observes that in the United States, the life course is generally viewed as a linear progression of events from birth to death in a predictable sequence. Life is an orderly process. Chronic and life-threatening illnesses challenge this view of continuity and order. Life is no longer predictable. During an acute crisis, a person's life is suspended. As the crisis subsides, the person must make sense of it to reestablish continuity and normality. Becker says, "Management of a serious chronic illness that has frequent ups and downs entails a continual reworking of identity." Many HIV-positive people suddenly realized they have a future, if limited, where there

had been none. The energy required to reorganize one's identity to move forward into the future, and the disappointment, frustration, and depression that can occur when the process must be repeated after a crisis, should not be underestimated. One consequence of chronic illness is that the responsibility for all aspects of management—physical, mental, and social—increasingly falls on the shoulders of those who have the illness. In the absence of a crisis, it is easy to forget that people with an illness are still working hard to care for themselves and to resume what could now constitute a normal life.

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Individualized stepped care of chronic illness

The routine care of people with chronic illnesses often fails to follow evidence-based guidelines or to achieve optimal outcomes.^{1,2} Because of the high prevalence and costs of chronic illness care^{3,4} and the key role of primary care physicians in managing chronic illness, enhancing care and outcomes in primary care settings is a public health imperative.

There are important general issues about how chronic conditions are effectively managed.^{1,5,6} Identifying these generalities is essential if the potential advantages of primary care of chronic illness are to be realized. Evidence-based guidelines for diverse chronic conditions identify similar elements of patient care (table).⁷⁻¹² These elements include a well-defined care plan, patient education, scheduled follow ups, outcome and adherence monitoring, the

targeted use of specialist consultation or referral, and the use of stepwise treatment protocols. Despite evidence that these elements of chronic illness care improve patient outcomes, they are often inadequately organized and delivered.¹

PROBLEMS IN CHRONIC ILLNESS CARE

The diagnosis and treatment of specific diseases are over-emphasized relative to developing a treatment plan with patients, patient education, setting a follow-up schedule, and managing the consequences of treatment in a patient's daily life.

The initial assessment is given greater emphasis than monitoring adherence and outcomes. In general, it is dif-

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